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Adolescent transgender health: Awareness does not equal resources

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Transgender care is a topic that has received greater social awareness and attention in popular culture in recent years. Awareness of transgender health care needs within the pediatric population has similarly increased as many centers experience a rapid rise in referrals. In the Netherlands, the Dutch Gender Identity Clinic saw progressively increasing numbers of pediatric and adolescent referrals through the early 2000s, with a gradual decrease in the mean age of adolescent referrals. Children's Hospital Boston saw a rapid quadrupling of cases soon after establishing their Gender Management Service in 2007. Our own endocrinology department has seen a dramatic increase in referrals since 2013, even without an established multidisciplinary clinic. This is thought to be a result of greater social acceptance and increasing exposure in the media, making it less threatening for a transgender individual to come out, rather than to an increasing prevalence of the condition. Prevalence estimates vary widely depending on how transgender is defined, the population surveyed, and how the data were collected. Although it was thought to be rare within the general population, 1 in 7000–20,000 natal males and 1 in 33,000–50,000 natal females, these numbers are likely underestimates due to the persistent social stigma. In fact, the prevalence of transgender identity may be as high as 355 per 100,000, or about 0.35% of the general population based on a recent meta-analysis by Collin, et al. [J Sex Med, 13(4):613, 2016].

Two sets of guidelines are commonly used for the endocrine transition of transgender adults and adolescents: the 2009 Endocrine Society Clinical Practice Guidelines (currently undergoing revision) and the World Professional Association for Transgender Health (WPATH) Standards of Care, Version 7. The two guidelines largely match with regards to the medical transition of transgender adolescents and recommend the use of GnRH analogs soon after the onset of endogenous puberty, followed by administration of gender affirming hormones (testosterone for transgender males and estradiol for transgender females), after age 16. Although it remains controversial, many practitioners recommend liberalizing the age at initiation of gender affirming hormone treatment in selected cases, and the upcoming revision of the Endocrine Society guidelines, expected by the end of 2016, will likely allow for increased flexibility in timing.

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Despite this, a recent survey at the 2015 annual meeting of the American Association of Clinical Endocrinologists showed that even among endocrinologists, 74% assessed themselves as “not at all” or “a little” competent in transgender care. Therefore, awareness has not necessarily been paralleled by resources, medical knowledge, or proficiency, and numerous gaps persist in delivering optimal healthcare in this population.

Many studies document the high incidence of psychological comorbidities experienced by transgender youth. These include high rates of bullying and harassment, frequent victimization by violence, increased rates of substance abuse and misuse of prescription drugs, high-risk sexual behaviors resulting in increased incidences of sexually transmitted infections including HIV, and most concerning, a high prevalence of self-harm and suicidality. Evidence suggests that many of these comorbidities are exacerbated by family and peer rejection, and there appears to be a link between bullying and substance abuse. As mentioned earlier, health care providers often have received little education or training in the care of transgender individuals. Although efforts in this regard are increasing, young transgender adults are frequently reluctant to engage the healthcare system, in part because of concerns for bias and discrimination and the often-correct perception that primary care providers have inadequate knowledge of transgender healthcare. In particular there is a deficiency of mental health providers with sufficient expertise to care for transgender adolescents. Furthermore, it is not always easy to locate those providers who do have such expertise. Both the Endocrine Society and WPATH guidelines emphasize the critical nature of careful psychological evaluations and provision of continuing mental health services to this population.

Additionally, there are many financial barriers to care in the adolescent transgender population. For example, GnRH analogs are prohibitively expensive without insurance authorization, typically costing \$15,000–20,000 per year for depot preparations of leuprolide acetate or a histrelin subdermal implant. Insurance companies often deny coverage of these medications for transgender teens. Although a lower cost option exists (a histrelin implant marketed for use in men with prostate cancer), coverage for this also is frequently denied by insurance carriers. Less expensive options for suppression of endogenous sex hormone effects include spironolactone for transgender males and depot medroxyprogesterone acetate for transgender females. However, these alternatives are less effective than GnRH analogs and may have additional adverse effects, i.e., electrolyte abnormalities and weight gain.

Recently, the US Department of Health and Human Services released the “final rule” clarifying the application of Section 1557 of the Affordable Care Act, which provides protection against healthcare discrimination on the basis of sex, race, age, and other characteristics. This rule appears to prohibit denial of transgender care by HHS-funded entities and insurance plans offered in the Health Insurance Marketplace. As the effects of this rule percolate through the healthcare system and the courts, there is hope that the financial coverage of transgender healthcare will improve.

Research is an additional area that is insufficient in the transgender patient population. Despite the growing numbers of transgender patients presenting to our clinics, the spectrum of gender dysphoria is broad and subsequent treatment decisions can vary widely, making

well-powered studies difficult to conduct. Therefore, existing recommendations for laboratory and clinical monitoring during puberty suppression or gender affirming hormone therapy are extensive and largely address theoretical risks of treatment rather than clinical evidence of adverse events in this population. Currently, practitioners for the most part rely on expert opinion and insight drawn from analogous physiological conditions to guide ongoing treatment decisions.

In addition, transgender care is itself still a new and emerging field, and shifts in definition and understanding impact clinical care. An accurate grasp of patient outcomes is essential for providing treatment recommendations and anticipatory guidance. Unfortunately, much of our current understanding of therapeutic needs, monitoring, and outcomes is built upon research performed when gender dysphoria/gender identity disorder was more broadly defined than the current designation and treatment methods were more variable. For example, previous studies reported that the great majority of prepubertal children with gender dysphoria “desisted” by the time they reached the early stages of puberty. It is postulated, however, that true rates of desistance are lower and persistence higher within today’s “gender dysphoria” population compared to the earlier studies that had broader inclusion criteria. Research confirming these suspicions has not actually been repeated.

Likewise, some studies have suggested that poor mental health outcomes in transgender youth can persist even after treatment. However, gradual refinement of accepted practice makes the treatment standards in these studies outdated. In addition, such studies often were not conducted with truly comparable control groups, limiting our ability to draw confident conclusions. The group in the Netherlands has followed a treatment cohort of 55 adolescents and has found promising psychological outcomes in the early post-treatment period. Nevertheless, long-term medical and mental health outcomes after care according to the current standard are largely unknown, and will remain unknown for years.

Transgender youth today live in an environment that is far more open and accepting than it was just a few years ago, but there remain many difficulties for them to overcome. Furthermore, in light of the above issues, transgender healthcare still has a long way to go. Additional funding for research into mental health outcomes; effectiveness of treatment modalities; and social, economic, and healthcare disparities is clearly needed. Additional education of the public and government representatives is also needed to further decrease bias and the stigma attached to being transgender in the U.S. today.